



## Supporting parents caring for a child with a learning disability

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### **Summary**

Parenting a child with a learning disability is a unique and often demanding experience. For some parents, the journey is one of chronic sorrow with stress and burden common experiences. The learning disability nurse can play a key role in supporting parents and families by adopting a humanistic approach to communicating effectively, providing information and working in partnership.

The aim of this article is to highlight to learning disability nurses and all professionals working with those who have a learning disability the issues arising for parents of a child with a learning disability. It is hoped that raising awareness of the issues that parents experience will equip nurses and other professionals working in the field of learning disability to work more effectively with these parents and children. This article offers suggestions for learning disability nurses on how they can enhance their role in supporting parents.

## **Stress and burden**

The news that a child has, or is at risk of, a learning disability is often one of the most frightening and confusing pieces of information that parents will receive (Fraley 1990, Beckman and Beckman Boyes 1993). At diagnosis, parents often describe a state of shock, denial, numbness, confusion and sorrow (Davis 1993, Saetersdal 1997, Kearney and Griffin 2001, Maxwell and Barr 2003).

The addition of a child in any family will cause disruption in one form or another and may be a stressor that produces some level of disorganisation. When a child is born with a learning disability, the rate of disturbance in a family rises to between 30% and 35% as opposed to 10% to 15% in the non-disabled family (Davis 1993). This disturbance arises because parents may find it difficult to maintain a family routine, especially when provision of support services is poorly co-ordinated (Redmond and Richardson 2003). The literature is unequivocal in identifying parental experiences in having a child with a learning disability with two commonly recurring themes, namely, stress and burden (McLinden 1990, Ray and Ritchie 1993, Dyson 1997, Keating 1997, Kearney and Griffin 2001). Nevertheless, studies also highlight parents' positive views of parenting a child with a learning disability (Hastings *et al* 2002, Olsson and Hwang 2003, Redmond and Richardson 2003).

In a comparative study, Dyson (1997) reported that fathers and mothers of

school-age children with learning disabilities expressed significantly greater amounts of parental stress than fathers and mothers of school-age children without disabilities. The basis of such stress arose from a variety of sources, such as visibility of the disability, the educational placement, difficulty in securing babysitters and lack of information about coping with pre-adolescent problems. The finding that fathers experienced as much stress as mothers is important. The father can sometimes be classified as 'peripheral parent' (Herbert and Carpenter 1994) resulting in mothers being provided with more opportunity to ventilate their feelings. Similar issues were reported by Redmond and Richardson (2003), who highlighted the financial impact on parents caused by the mother ceasing employment to care for the child and the cost of accessing specialised services, such as private physiotherapy or speech therapy. However, a Swedish study reported parents' minimised financial strain (Olsson and Hwang 2003). Swedish families with children with a learning disability receive governmental financial assistance aimed at addressing the impact of additional costs and loss of income (Olsson and Hwang 2003).

Stresses for parents change in nature over time. Evidence to suggest this was provided by a longitudinal study of families with developmentally delayed children, where it was reported that the focus of stress shifted from exclusion, desperation and the fight for recognition, to acceptance and rights (Saetersdal 1997). McLinden (1990) reported no mention of joy, hope or optimism in a study involving mothers (n=48) and fathers (n=35). Central themes emerging in this

study were all related to stress, namely worry, fatigue and limited social relationships, findings consistent with those reported by Rourke (2000). However, it is important to highlight that many parents attributed their feelings of depression to work overload and little time left for themselves (Olsson and Hwang 2003). Moreover, Keating (1997) found evidence to support the view that parents develop some positive perceptions over time. Although depression, pain, despair, sadness and emotional exhaustion were central themes in Keating's (1997) descriptive phenomenological study drawn from carers (n=28) who had a child with a severe and/or profound learning disability, respondents also reported that the child brought positive contributions, as illustrated in the following comments: 'I possess a less selfish and more tolerant perspective, with a greater respect for life and simple pleasures'; 'My child has taught me to love unconditionally'; and 'You grow in awareness and the experience has great potential for human growth'.

While it is important to highlight that the majority of families with a child who has a learning disability develop coping mechanisms to continue their lives normally (Koller *et al* 1992), some families do not cope so well and experience chronic sorrow.

### **Chronic sorrow**

Parents of a child with a learning disability experience fluctuating emotions which may lead to what is termed 'chronic sorrow'. Seminal work by Olshansky (1962)

described chronic sorrow as a parental response to a mentally disabled child. He indicated that parents of children with a learning disability struggled to cope with the loss of a 'perfect child', characterised by recurring waves of grief and sadness. Teel (1991) also suggested that sadness was exacerbated at critical periods, such as Birthdays, Christmas, start of school age. She emphasised that when parents realised that they had a disabled child instead of their hoped-for child, chronic sorrow ensued. Following their qualitative study of the experiences of parents (n=6), Kearney and Griffin (2001) concluded that pain and sorrow were integral to the experience of being a parent of a child with a significant developmental disability.

Drotar *et al* (1976) identified a common sequence of reactions in a conceptual framework, namely, shock, denial, sadness, adaptation and reorganisation. This framework was similar to the middle-range theory of chronic sorrow proposed by Eakes *et al* (1998), derived from interviews with individuals (n=196) who had experienced loss. This theory viewed chronic sorrow as a normal response to an abnormal situation and proposed that trigger events, such as milestones, are closely connected to chronic sorrow.

Drotar *et al*'s (1976) framework of reactions was evident in the findings of a longitudinal study on parents (n=12) learning to cope with their child's diagnosis (Gibson 1995). The parents expressed emotions of bewilderment, shock, confusion, fright, anxiety and anger. Similar emotions of denial, grief, guilt, anger, and fear were also reported elsewhere (Johnston and Marder 1994).

The experience of chronic sorrow is triggered differently for mothers and fathers of children with a severe learning disability. Mallow and Bechtel (1999) surveyed parents (n=28; 19 mothers and nine fathers) attending a support group using Burke's Chronic Sorrow Questionnaire, and reported that patterns of grief and sadness re-emerged and were more consistent among mothers. Of significance was the finding that management crises triggered recurring sorrow in mothers, while comparison with social norms saddened fathers.

### **Marital pressures**

Redmond *et al* (2002) reported from their study of mothers (n=17) that having a child with a developmental disability placed a strain on their personal relationship, with the couple spending little time together. Moreover, decreased marital satisfaction influenced feelings of support and a sense of isolation experienced by each parent (Beckman 1996). However, Keating (1997) revealed that while many parents considered their child to adversely affect the relationship, some viewed their child as strengthening the relationship. Taanila *et al* (1998) reported that many of the parents (n=85) in their study expressed their marital relationship had become closer. Interestingly, Taanila *et al* (2002) found that an indicator of good family cohesion was when spouses supported each other and shared the caretaking tasks and other housework equally.

## Parents' coping strategies

The coping styles of parents who have children with a learning disability can be classified into internal and external strategies (Turnbull *et al* 1986). External strategies such as acquiring social support and formal support from organisational and community resources are the most commonly used. Taanila *et al* (2002) reported that high-coping families had an optimistic attitude and used open communication. In addition, parents may find taking up a previous hobby assists them in coping.

Ray and Ritchie (1993) reported on parents' (n=23) perceptions of coping strategies and revealed that practical support and cohesiveness significantly influenced parents' coping strategies. This finding is consistent with that of Todd *et al* (1993) who reported that support was an important factor in determining the success with which carers of disabled children coped. Moreover, the role played by spiritual support and God was linked to maintaining hope. The role of spiritual support in coping was also reported by Ray and Ritchie (1993). Seeking spiritual support (and also social and formal support) was identified by parents as the most important external coping strategy (Turnbull *et al* 1986).

The manner in which information is given to parents can affect their coping strategies and adjustments. Truthful information is significant in helping parents cope with their child. Kerrel (2001) indicated that a lack of information at diagnosis reinforced feelings of isolation with no support. Similar findings were



reported by Gibson (1995) following a fieldwork study of mothers (n=12). It was reported elsewhere that adequate information about their child's disability appeared to be a 'very important determinant of parental coping' (Taanila *et al* 2002).

Practical strategies also assisted in parents' coping, with the need for respite care regarded highly by parents (Datta *et al* 2002, Olsson and Hwang 2003). It is important to note that some parents wanted respite care to be provided in their own homes (Redmond and Richardson 2003).

### **The nurse's role in supporting parents**

The registered nurse qualified in the specialism of learning disability supports parents by communicating effectively, providing information and working in partnership with parents. Positive effects of partnership with nurses were reported by Leik and Chalkley (1990), who emphasised that involving parents in their child's programme helped them to see their child more positively. This partnership is crucial in the context of reported interprofessional rivalry which can upset and confuse parents (McCray and Carter 2002). In addition, it is essential for learning disability nurses to never underestimate the trust that parents place in them, and to respect this trust at all times.

The greatest expressed need of parents was their need for information regarding their child's disability (King *et al* 1999, Smith and Daughtrey 2000, Balling and

McCubbin 2001). It is argued that sharing information is an important step in building a working relationship while withholding information can adversely affect the relationship (Gibson 1995, Beckman 1996). However, mothers of children with profound learning disability reported that the process of obtaining information could be 'haphazard', with sometimes 'conflicting answers' (Redmond and Richardson 2003), further emphasising the need for learning disability nurses to share accurate and useful information with parents.

Information sharing can be through training to parents and professionals whereby both parties learn from one another and develop an understanding of one another's role and viewpoint (Rourke 2000). Mothers reported wanting a service that was 'flexible' and supportive to the caring role already undertaken by families, rather than having 'unsuitable services' imposed on them (Redmond and Richardson 2003). Such an approach requires reciprocity between the learning disability nurse and parent. This reciprocity was proposed in the 'Partnership Model', which identified four basic principles, namely, mutual respect and recognition, sharing of information and skills, sharing of feelings and sharing of decision making (Carpenter 1997).

Parents reported the stress of having to undergo evaluations to be eligible for support (Olsson and Hwang 2003). Parents experiencing a sense of powerlessness and lack of privacy require the learning disability nurse to play a

key role in minimising this stress by supporting them sensitively and assisting in co-ordinating services. However, Barr (2006) cautioned that the co-ordinating role of the community nurse (learning disability) may not be the 'most effective use' of specialist knowledge and skills. Moreover, the community nurse (learning disability) may experience blurring of roles with other professional workers (Culley and Genders 1999, McCray and Carter 2002). Nevertheless, a role in co-ordinating services reflects the view that the learning disability nurse should also be educated in social work skills (McCray and Carter 2002). Joint programmes in nursing and social work have resulted in learning disability practitioners who have a wide range of knowledge in both health and social care needs (Davis et al 1999).

The learning disability nurse also plays a key role in supporting parents to take time for themselves. However, parents will be reluctant to take this time together if they worry that their child will not be well taken care of, highlighting the need for well-functioning respite care (Olsson and Hwang 2003). Furthermore, the learning disability nurse has the potential to raise parents' self-esteem by helping them 'identify priorities in life besides the care of their children' (Tam and Cheng 2005). Parents with a more positive concept of self may use external coping strategies, such as joining training courses or attending self-help groups (Tam and Cheng 2005), or taking up a previous or new hobby.

The 'human-to-human relationship' proposed by the American nurse theorist, Joyce Travelbee (1971), is also useful in understanding the essence of the learning disability nurse's role. This relationship involves a rapport whereby the nurse can assist parents to find meaning in their experience (Travelbee 1971). Such a relationship fosters the needs of the family where the nurse perceives, responds to and appreciates the uniqueness of the parent, with compassion, honesty, empathy and sympathy being fundamental characteristics of the relationship. This relationship was highlighted by Ford and Turner (2001) in a hermeneutic phenomenological study with nurses (n=4). The nurses interviewed described the significance of forming a 'special relationship' with the child and the family. Such a relationship was enriching, with nurses expressing personal growth as a result of their relationship with the child and family. Ford and Turner (2001) also reported that the development of trust between the nurse and family should be established before forming this relationship, consistent with findings reported elsewhere (Simeonsson *et al* 1995, Thorsteinsson 2002). Such trust is promoted when professionals acknowledge their self-awareness in the parent-professional relationship (Kirk 2001). Acute self-awareness is essential, as active and focused listening is a key skill in developing partnership with parents (Beckman 1996). Furthermore, self-disclosure requires an acute degree of self-awareness, which develops over time and with experience (Dowling 2006).

Good listening involves listening to what is being said as well as how it is said and what is not said. Parents should be listened to. Mothers in Redmond and

Richardson's (2003) study expressed a need for emotional support and having someone to talk to. However, learning disability nurses should remember that there can be considerable difference between the emotions professionals perceive families are experiencing and the emotions parents report themselves (Simeonsson *et al* 1995). This further emphasises the need for sharing of feelings in the nurse's relationship with parents.

Empathy is an important building block in the relationship (Davis 1993, Beckman 1996). It is the art of being able to understand and feel for a family without becoming over-involved. Nurses should recognise that chronic sorrow is an understandable and 'non-neurotic response to a real-life tragedy' (Krafft and Krafft 1998). Nurses' knowledge of chronic sorrow theory can empower them to help parents make better sense of their emotions. However, it is important to acknowledge that parents respond uniquely in their mourning process and nurses should remain open to each parent's unique response.

Conflicting opinions surrounding the advocacy role of learning disability nurses for their clients were highlighted by Llewellyn (2004). However, it is argued that the learning disability nurse should act as an advocate on behalf of the family as they may not have the stamina to seek out assistance when needed (Krafft and Krafft 1998). This was clearly illustrated in the following comment from a participant in Olsson and Hwang's (2003) study: 'The power you need to take care of the child is wasted on finding out about services...'. There is therefore a

need for learning disability nurses to expand ways in which they can share in information gathering and decision making with parents. This latter point further emphasises the relevance of health and social work skills required by learning disability nurses (McCray and Carter 2002).

## **Conclusion**

Having a child with a learning disability requires parents to deal with and adapt to new and extensive demands. The personal coping strategies that parents adopt can be sustained by support from the learning disability nurse. Parents' emotions are not static but constantly react and change over time and in response to situational factors. The learning disability nurse can be instrumental in providing much-needed support for parents through a humanistic approach. Establishing a rapport where there is honesty, trust, compassion and flexibility is essential. Learning disability nurses should have a passion for their role, support and educate with humour and hope and embrace a commitment to develop the potential of each client, in a climate of genuine respect. Ultimately, the child will reap the benefits.

## **References**

- Balling K, McCubbin M (2001) Hospitalized children with chronic illness: parental caregiving needs and valuing parental expertise. *Journal of Pediatric Nursing*. 16, 2, 110-119.
- Barr O (2006) The evolving role of community nurses for people with learning disabilities: changes over an 11-year period. *Journal of Clinical Nursing*. 15, 1,

72-82.

Beckman PJ (1996) *Strategies for Working with Families of Young Children with Disabilities*. Brookes Publishing, Baltimore MD.

Beckman PJ, Beckman Boyes G (1993) *Deciphering the System: A Guide for Families of Young Children with Disabilities*. Brookline Books, Cambridge MA.

Carpenter B (Ed) (1997) *Families in Context: Emerging Trends in Family Support and Early Intervention*. David Fulton Publishers, London.

Culley L, Genders N (1999) Parenting by people with learning disabilities: the educational needs of the community nurse. *Nurse Education Today*. 19, 6, 502-508.

Datta SS, Russell PSS, Gopalakrishna SC (2002) Burden among the caregivers of children with intellectual disability: associations and risk factors. *Journal of Intellectual Disabilities*. 6, 4, 337-350.

Davis H (1993) *Counselling Parents of Children With Chronic Illness Or Disability*. Brookes Publishing, Baltimore MD.

Davis J, Rendell P, Sims D (1999) The joint practitioner – a new concept in professional training. *Journal of Interprofessional Care*. 13, 4, 395-404.

Dowling M (2006) The sociology of intimacy in the nurse-patient relationship. *Nursing Standard*. 20, 23, 48-54.

Drotar D, Baskiewicz A, Irvin N, Kennell J, Klaus M (1976) The adaptation of parents to the birth of an infant with a congenital malformation: a hypothetical model. *Pediatrics*. 56, 5, 710-717.

Dyson LL (1997) Fathers and mothers of school-age children with developmental disabilities: parental stress, family functioning, and social support. *American Journal of Mental Retardation*. 102, 3, 267-279.

Eakes GG, Burke ML, Hainsworth MA (1998) Middle-range theory of chronic sorrow. *Image: Journal of Nursing Scholarship*. 30, 2, 179-184.

Ford K, Turner D (2001) Stories seldom told: paediatric nurses' experiences of caring for hospitalized children with special needs and their families. *Journal of Advanced Nursing*. 33, 3, 288-295.

Fraley AM (1990) Chronic sorrow: a parental response. *Journal of Pediatric Nursing*. 5, 4, 268-273.

Gibson CH (1995) The process of empowerment in mothers of chronically ill children. *Journal of Advanced Nursing*. 21, 6, 1201-1210.

Hastings RP, Allen R, McDermott K, Still D (2002) Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*. 15, 3, 269-275.

Herbert E, Carpenter B (1994) Fathers- the secondary partners: professional perceptions and a father's recollections. *Children and Society*. 8, 1, 31-41.

Johnston CE, Marder LR (1994) Parenting the child with a chronic condition: an emotional experience. *Pediatric Nursing*. 20, 6, 611-614.

Kearney PM, Griffin T (2001) Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing*. 34, 5, 582-592.

Keating M (1997) *Caring for the Carer: Enhancing the Health and Well-being of Parents of Children with Multiple Special Needs*. Unpublished Master's thesis. University College Galway, Ireland.

Kerrell H (2001) Service evaluation of an autism diagnostic clinic for children. *Nursing Standard*. 15, 38, 33-37.

King G, King S, Rosenbaum P, Goffin R (1999) Family-centered caregiving and well-being of parents of children with disabilities: linking process with outcome. *Journal of Pediatric Psychology*. 24, 1, 41-53.

Kirk S (2001) Negotiating lay and professional roles in the care of children with complex health care needs. *Journal of Advanced Nursing*. 34, 5, 593-602.

Koller H, Richardson SA, Katz M (1992) Families of children with mental retardation: comprehensive view from an epidemiologic perspective. *American Journal of Mental Retardation*. 97, 3, 315-332.

Krafft SK, Krafft LJ (1998) Chronic sorrow. Parents' lived experience. *Holistic Nursing Practice*. 13, 1, 59-67.

Leik RK, Chalkley MA (1990) Parent involvement: What is it that works? *Children Today*. 19, 3, 34-37

Llewellyn P (2004) Nursing and advocacy in person centred planning. *Learning Disability Practice*. 7, 9, 14-17.

Mallow GE, Bechtel GA (1999) Chronic sorrow: the experience of parents with children who are developmentally disabled. *Journal of Psychosocial Nursing and Mental Health Services*. 37, 7, 31-35.

Maxwell V, Barr O (2003) With the benefit of hindsight: a mother's reflections on raising a child with Down Syndrome. *Journal of Intellectual Disabilities*. 7, 1, 51-64.



McCray J, Carter S (2002) A study to determine the qualities of a learning disability practitioner. *British Journal of Nursing*. 11, 21, 1380-1388.

McLinden S (1990) Mothers' and fathers' reports of the effects of a young child with special needs on the family. *Journal of Early Intervention*. 14, 3, 249-259.

Olshansky S (1962) Chronic sorrow: a response to having a mentally defective child. *Social casework*. 43, 90-193.

Olsson MB, Hwang PC (2003) Influence of macrostructure of society on the life situation of families with a child with intellectual disability: Sweden as an example. *Journal of Intellectual Disability Research*. 47, Pt 4-5, 328-341.

Ray LD, Ritchie JA (1993) Caring for chronically ill children at home: factors that influence parents' coping. *Journal of Pediatric Nursing*. 8, 4, 217-225.

Redmond B, Bowen A, Richardson V (2002) *The Needs of Carers of Fragile Babies and Young Children with Severe Developmental Disability*. Centre for the Study of Developmental Disabilities and Department of Social Policy and Social Work, University College Dublin, Dublin.

Redmond B, Richardson V (2003) Just getting on with it: exploring the service needs of mothers who care for young children with severe/profound and life-threatening intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. 16, 3, 205-218.

Rourke C (2000) *Couples Work in the Context of an Early Intervention Service: A Systematic Analysis*. Unpublished Family Therapy Certificate dissertation. Clanwilliam Institute, Dublin.

Saetersdal B (1997) Forbidden suffering: the Pollyanna syndrome of the disabled and their families. *Family Process*. 36, 4, 431-435.

Simeonsson RJ, Edmondson R, Smith T, Carnahan S, Bucy JE (1995) Family involvement in multidisciplinary team evaluation: professional and parent perspectives. *Child: Care, Health and Development*. 21, 3, 199-215.

Smith L, Daughtrey H (2000) Weaving the seamless web of care: an analysis of parents' perceptions of their needs following discharge of their child from hospital. *Journal of Advanced Nursing*. 31, 4, 812-820.

Taanila A, Jarvelin MR, Kokkonen J (1998) Parental guidance and counselling by doctors and nursing staff: parents' views of initial information and advice for families with disabled children. *Journal of Clinical Nursing*. 7, 6, 505-511.

Taanila A, Syrjala L, Kokkonen J, Jarvelin MR (2002) Coping of parents with

physically and/or intellectually disabled children. *Child: Care, Health and Development*. 28, 1, 73-86.

Tam SF, Cheng AW (2005) Self-concepts of parents with a child of school age with a severe intellectual disability. *Journal of Intellectual Disabilities*. 9, 3, 253-268.

Teel CS (1991) Chronic sorrow: analysis of the concept. *Journal of Advanced Nursing*. 16, 11, 1311-1319.

Thorsteinsson LS (2002) The quality of nursing care as perceived by individuals with chronic illnesses: the magical touch of nursing. *Journal of Clinical Nursing*. 11, 1, 32-40.

Todd S, Shearn J, Felce D, Beyer S. (1993) Careers and caring: The changing situations of parents caring for an offspring with learning disabilities. *The Irish Journal of Psychology*. 14, 1, 130-153)

Travelbee J (1971) [Q publication date is 1971 on amazon? *Interpersonal Aspects of Nursing*. FA Davis, Philadelphia PA.

Turnball P, Summers JA, Brotherson MJ (1986) Theoretical and empirical implications and future directions for families with mentally retarded members. In Gallagher JJ, Bietze PM (Eds) *Families of the Handicapped Persons: Research, Programs and Policy Issues*. Brookes Publishing, Baltimore MD, 45-65.